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Abbreviations: DRNO; do-not-resuscitate order – GFRUP; Groupe Francophone de Réanimation et Urgence Pédiatriques (French-speaking group of paediatric intensive and emergency care) – PICU; paediatric intensive care unit - NPICU neonatal and paediatric intensive care unit; – POPC score; Paediatric Overall Performance Category score – PIM2 score; Paediatric Index of Mortality score – DMP; decision-making process.

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Abstract

Purposes: our goal was to assess the prevalence of questioning about the appropriateness of initiating or maintaining life sustaining treatments (LST) in French speaking PICUs and to evaluate time utilisation related to decision-making processes (DMP). **Methods**: 18-month multicenter, prospective, descriptive, observational study in 15 French speaking PICUs. **Results**: among the 5602 children admitted, 410 died (7.3%) including 175 after forgoing LST (42.7% of deaths). LST was questioned in 308 children (5.5%) with a prevalence of 13.3 per 100 patient-days. More than 30% of children survived despite the appropriateness of LST being questioned (23% despite a decision to forgo treatment). Median caregiver's time spent on making and presenting the decisions was 11 hours per child. **Conclusions:** In this study, on any given day in each 10 bed PICU there was more than one child for whom a DMP was underway Twenty-three per cent of children survived despite a decision to forgo LST was made, which underlines the need to elaborate a care plan for these children. Also DMP represented a large amount of staff time that is undervalued but necessary to ensure optimal palliative practice in PICU.

In developed countries, most children die in paediatric intensive care units (PICU) [1-2], where forgoing life-sustaining treatment (LST) is the most common mode of death with variable international practice [3-12]. Previous studies predominantly focused on patients who died, excluding children for whom the possibility to forgo LST was discussed but not implemented, and those who survived after a decision to forgo. Only a few described both decision-making processes (DMP) and end-of-life care [13-14]. Though published guidelines contain recommendations to ensure collaborative decisions [15-19], time consumed by DMP remains undocumented.

This multicenter, prospective study describes the forgoing of LST in francophone PICUs and units caring for both neonates and children (Neonatal and Paediatric Intensive Care Units: NPICU). We assessed prevalence of questioning about appropriateness of LST and evaluated time utilisation related to DMP.

PATIENTS AND METHODS

The 35 NPICUs/PICUs affiliated to the francophone paediatric intensive care network (GFRUP) were invited to participate: 17 agreed and 15 provided the information requested. From June 15, 2006 to November 1, 2007, all consecutively admitted children were included. Preterm newborns (birth before 37 weeks of pregnancy) were excluded.

Definitions

Life sustaining treatment (LST) was defined as techniques to sustain respiratory, cardiovascular or renal function. *Mode of death* was classified as: (1) withdrawing LST, defined as active discontinuation of LST; (2) withholding LST, defined as refraining from any new LST; (3) death after a do-not resuscitate (DNR) order, defined as only refraining from attempting resuscitation in case of cardiac arrest; (4); death after full medical intervention and (5) brain death [20].

DMP began as soon as an individual (caregiver, parent, or the child himself) wondered about LST and ended when the child died or was discharged. *Decision regarding LST* was defined as the record, prior to the terminal event, of the medical decision (full medical intervention, DNR, withholding LST, withdrawing LST).

DMP were classified as (1) complete DMP (record of a decision and at least one decision-making meeting), (2) abbreviated DMP (record of a decision but no data concerning decision-making meeting), (3) interrupted DMP (record of the date of the beginning of DMP, but no data concerning meeting and decision). We defined undocumented DMP when the recorded mode of death indicated that LST had been forgone with no record of a DMP. *Parents' wishes* were classified into: maximum treatment, forgoing treatment, "doctors should decide", and not expressed. *Decision justifications* were classified according to the Royal College of Paediatrics and Child Health [17]: (1) permanent vegetative state (the child will not react or relate with the outside world), (2) no chance

situation (LST simply delays death without significant alleviation of suffering), (3) no purpose situation (the degree of impairment will be so great that it is unreasonable to expect the child to bear it), (4) unbearable situation (child and/or family feel that further treatment is more than can be borne), and (5) unclassifiable. Parents' rea*ctions after the decision* were classified into: (1) opposition, (2) resignation, (3) approval, or (4) not expressed. *Sedation after a decision to forgo* was classified into: (1) unchanged, (2) doubled/tripled, (3) quadrupled/quintupled, and (4) more than quintupled dose. Potassium chloride or neuromuscular blocking agent administration before withdrawing mechanical ventilation was defined as euthanasia. Because of potential litigation, , a 12.5% proportion of positive answers was forced in the database at random, to make the true positive answers unidentifiable. Final results were corrected, taking the 12.5% into account.

Data Collection and management

Demographics, dates of admission and discharge, mode of discharge or death, and main organ failure were recorded for all children. Severity was assessed by the PIM2 score [21] and the day 1 PELOD score (D1PELOD) [22]. Performance at admission and discharge was assessed by the POPC score [23].

As soon as a DMP was initiated, a form was completed by the attending senior intensivist. Dates, durations, participants, and decisions at each step of the DMP were recorded.

Previously trained physicians (one per centre) entered data into a web-based database that respects confidentiality requirements (Epiconcept™, Paris, France). A research assistant screened the database weekly as quality control, and sent an error report to investigators. One quality control visit was done in each centre during the study. Patient data were collected anonymously, but a nominative list was held by investigators for quality control.

Statistical methods:

Results were expressed as percentages, median values, and interquartile ranges. The Chi-square test and the Kruskal-Wallis test were used for comparisons. A p value < 0.05 was considered as significant. For statistical analysis, decisions to withhold, to withdraw LST and DNR order were pooled into a single "decision to forgo" category.

Ethical considerations:

Study design was approved by the ethical committee of the Société de Réanimation de Langue Française on June 29th 2006. The database was declared to the French authorities (CNIL) on May 3th 2006.

Results

Fifteen centres participated in the study, representing two thirds of the PICU beds of the collective. Number of beds per PICU/NICU was 12 (11 – 18), number of physicians 5 (3 – 7), and number of non-medical caregivers 30 (24 – 50).

Population

During the study, 5602 children were admitted (37192 days of stay), 410 died (7.3%). Median age was 12 months (1 – 66) and sex ratio 1.31. Probability of death predicted by PIM2 was 1.7% (.8 – 5.4), D1PELOD was 10 (1 – 11), POPC 1 (1 – 3) at admission, and 2 (1 – 3) at discharge, length of stay 2 days (1 - 6). Main organ failure at admission was: respiratory (44.4%), cardiovascular (19.6%), neurological (18.8%), and gastro-intestinal (5.0%).

Mode of death was: brain death in 66 (16.1%), death after full medical intervention in 169 (41.2%), after withholding LST in 37 (9.1%), after withdrawing LST in 87 (21.2%), and after DNR order in 51 (12.4%). Thus, 175 deaths (42.7%) followed a decision to forgo treatment.

Initiation of DMP

LST were questioned in 308 children (5.5%), by the attending physician in 281, by the child himself in 15, by nurses in 8, and by parents in 1. Delay for questioning was one day after admission (0 – 4). The prevalence of questioning was 13.3 per 100 patient-days. Of these 308 children, 189 (61%) died, representing 46% of all deaths. Comparison of these 308 children with the others appears in table 1.

Decision-making processes

Of the 308 DMP initiated, 220 (71.4%) led to at least one decision (total 269 decisions). Of these 220 children, 150 died after a decision to forgo (36.6% of deaths) and 7 despite a maximal treatment decision, 18 children survived after a maximal treatment decision and 45 survived despite a decision to forgo. Among these 220 DMP, 193 were complete and 27 were abbreviated. When comparing recorded modes of death and data regarding DMP, we observed that 25 children died after forgoing LST, while the anticipated decision had not been recorded (figure 1): 11 were interrupted DMP and 14 were undocumented DMP. The justifications of the 269 decisions are presented in table 2 and the corresponding last decisions in figure 1.

Preparing decisions

405 parent conferences were organised to discuss the possibility to forgo LST. Among the 220 children with at least one decision, 297 conferences were organised (2 per child (1 – 3)), duration 30 minutes (25 – 40) for each).

The attending nurse was present during 219 conferences (73.7%) and the referring resident during 104 (35%). An external expert estimated prognosis for 154 of these 220 children (70.0%).

Parents' opinions were recorded for 129 of the 193 children with complete DMP. Fathers' and mothers' opinions were similar for 82 (45 wishes to forgo, 18 "doctor should decide", 12 not expressed, 7 maximal treatment wishes). Among the 47 remaining cases with discrepancies between parents' opinions, wishes to forgo treatment versus maximal treatment were never recorded. Delay for obtaining parents' opinion was 5 (2 – 10) days after admission.

Decision-making

Two hundred and forty decision-making meetings were organized for 193 children (1 in 155 children, 2 in 31, 3 in 5, and 4 in 2) including 16 discussions during a routine staff meeting, 23 discussions at the bedside, and 201 dedicated meetings. The latter lasted 45 minutes (30 - 60) with 10 (8 – 12) participants. The PICU director attended 59.4% of these meetings, the head nurse 69%, a psychologist 24.4% and a chaplain 1.4%. At least one resident attended 90.3% [2 residents (1 – 3)], and a nurse 88% [1 nurse (1 – 2)]; 88.9% of nurses had cared for the patient for at least two days (1 - 5). At least one other nursing team member attended 40.1% of meetings [median 1 (0 – 2)], and an outside expert 70.5% [median 1 (0 – 2)].

The first meeting was planned 1 day (1 – 5.5) and was held 2 days (1 – 6) after initiating the DMP. During the 193 first meetings, there were 54 withdrawing decisions, 57 withholding decisions, 48 DNR orders, 22 consensual decisions to continue treatments and 7 decisions to continue treatment in the absence of consensus. In five cases no decision was made because some medical data were missing. Thirty previous decisions were modified during the 38 second meetings and 4 during the 7 third meetings. All but one change resulted in further limitation of treatment.

Parents were informed that there would be a meeting in 127 cases (52.9%); they knew the date in 100 (41.7%). Among the 193 complete DMP, 20 decisions to forgo were made where neither parent had expressed any wishes, and 5 where one parent previously requested maximal treatment.

Presenting and implementing the decisions

Among the 269 decisions, 233 were presented to parents (87.6%) by the intensivist in charge of the patient during a 30-minute (25 - 45) conversation. The referring resident and a nurse were present at 33.5% and 75.1% of these conferences, respectively.

Of the 193 children with complete DMP, 175 parents' reactions were recorded. Fathers' and mothers' reactions were similar for 122 (77 approvals, 42 resignations, 2 absence of reaction, 1 opposition). In one case,

the father voiced opposition to maximal treatment while the mother did not express any preference. In all other cases, the reactions were approval or resignation when the second parent did not expressed anything or was absent.

The 269 decisions were implemented after 9 days after admission (3.5 – 17). Considering only the final decision for each child (220 decisions), 134 (61%) led to major changes in treatment. These changes were implemented 1 day (0 - 3) after the decision. Among these 134, LST was withdrawn in 93 children (table 3). The intensivist in charge of the patient was present at the bedside during the implementation of the decision in 132 cases (98.5%), the referring nurse in 131 (97.8%) and the referring resident in 51 (38.1%). The option of being present was offered to parents for 121 children (90.3%) and 108 were present (80.6%). The two children whose parents were opposed to maximal treatment survived.

Outcome

In the 193 children with complete DMP, the interval between final decision and death or discharge was 2 days (1 – 3) and 6 days (2 – 9) respectively. The POPC at discharge was 4 (3 – 4) for the 52 children who survived after complete processes, 3.5 (2.5 – 4) for the 6 with abbreviated processes and 4 (4 – 6) for the 54 with interrupted processes. Clinical outcome appears in figure 1.

Time utilisation

For the 193 children with a complete DMP, the cumulative time for a whole decision-making process was 660 min per child (450 – 975), including 60 min per child (45 – 90) for preparing the decisions with parents, 400 min per child (240 – 65) for decision-making and 60 min (45 – 90) for presenting the decisions to parents.

DISCUSSION

In this study, the incidence of questioning about the appropriateness of LST was 5.5% of admissions and the prevalence 13.3 per cent patient-days. More than 42% of deaths followed a decision to forgo LST. More than 30% of children survived despite the appropriateness of LST being questioned (23% despite a decision to forgo). Median caregiver's time used for making and presenting the decisions was 11 hours per child.

Our recording of all the DMP as soon as the appropriateness of LST was questioned provides original data such as incidence and prevalence of questioning, time consumption, and outcome of children who survived, unavailable from previous studies that recorded only modes of death [11, 24-25]. The 13.3 per cent patient-day prevalence reflects a high level of routine questioning, as encouraged by the GFRUP's guidelines [18]. Even

though most guidelines published since 1994 recommended collaborative decisions [15-19, 26-28], caregivers' time consumption has never been studied. In a one-day cross sectional study in 90 French ICUs (6 PICUs), end of life conferences lasted 31.5 minutes, similar to our data [29]. In our study, time for making and presenting each decision represented an important investment for PICU teams, especially as it did not account for time to implement decisions. The physician-nurse partnership remains central to multidisciplinary care and the PICU team-family partnership permits the child's best interest to be determined together. Organising these partnerships needs time, which should be better valued by health system compensation policies to promote palliative practices in PICU.

The fact that modes of discharge or death and data regarding DMP were separately recorded is another original feature of our study. We observed that 14.3% of deaths following a decision to forgo LST occurred with no record of a decision-meeting or bedside discussion. French law pertaining to patients' rights at the end of life [30] requests exhaustive recording of all DMP, thus these deaths may be considered as potential malpractice. In our study, the decision was recorded prior to the terminal event in two thirds of DMP. The main treatments withdrawn were mechanical ventilation and vasoactive drugs. Sedatives that were administered when LST were withdrawn were benzodiazepines and opiates, in accordance with published end of life practices in PICUs [4, 7, 10, 14, 31]. Most children received usual to triple doses of sedatives, as reported in retrospective studies in US PICUs [7, 14]. Neuromuscular blocking agents and potassium chloride were used below the 12.5% detection threshold induced by our anonymisation methodology. Finally, most children who died after a decision to forgo were accompanied by their parents (>80%), referring nurse (>97%) and referring physician (>98%). Thus, incorporation of palliative practices into PICU, the main goal of the GFRUP's guidelines, has been successfully achieved. The main difficulties in implementing the guidelines were anticipating the correct date for the decision-making meeting (mostly scheduled for the following day). This partly explains why 12% of decision-making meetings were organized without a nurse and 11% with a nurse in charge of the patient for the first time. We do not know why DMP was interrupted before a decision had been made for 56 children who survived. Was the process fair for these children who had developed severe neurological sequelae? Future guidelines should indicate that all initiated processes must be continued until a decision to forgo or continue LST.

Another important result is that 23% of children survived despite a decision to forgo. This outcome has only previously been reported in adults (9.5% of ICU patient survived despite a decision to forgo was made in ICU) [32]. This high proportion indicates the need for a care plan for these children and raises the problem of acceptability of PICU decisions by subsequent teams [33-34]. Further guidelines should address this to improve continuity of care for these children [33, 35].

When compared to the results of the previous French multicentre study undertaken in 1999 [25], our study demonstrates interesting trends regarding the evolution of practice since guidelines were written [18] and French law acknowledged the right for physicians to forgo treatments [30]. In the previous study, deaths following a decision to forgo represented 43% of total deaths. This indicates that the legalisation of forgoing treatments has not increased this proportion, even though it reduced the risk of litigation. Since 1999, the main improvement in practice relates to the involvement of nurses (nurse participation at decision-making meetings increased from 46% to 88%) and information given to parents (parents aware of the decision-making meetings increased from 11% to 53% and presentation of the decisions from 19% to 87%). Surprisingly, parents' opinion was formally recorded prior to only 46.3% of decisions. This contrasts with the quasi-exhaustive information given to parents after the decisions. However, data about parents' wishes and reactions showed that physicians did not seek informed consent, but absence of opposition. Even though the shared decision model is gaining ground, the GFRUP's guidelines recommend giving parents choice regarding their level of involvement in the DMP. A recent qualitative study, reported that French parents agreed that LST decisions should be made by physicians [36], and French law has ratified that the physician who is in charge of the patient must be the bearer of the decision, after listening parents' wishes and obtaining the advice of an external consulting colleague [30, 37].

The main limitation of our study is its self-monitoring design. Because of the absence of an independent investigator, discrepancies between perceived and true parent satisfaction could not be studied. Nevertheless, the exhaustive inclusion of more than 5000 PICU children provides new insights such as the incidence of questioning and time consumed by DMP. Moreover, this study gives updated data concerning forgoing treatment in PICUs, useful in improving the guidelines and end of life care in PICU.

CONCLUSIONS

The prevalence of questioning about the appropriateness of LST was 13.3 per 100 patient-days, so on any given day in each 10 bed PICU, there was more than one child for whom a DMP was underway. Twenty-three per cent of children survived despite a decision to forgo LST, which underlines the need to elaborate a care plan for these children. Also DMP represented a large amount of staff time that is undervalued but necessary to ensure optimal palliative practice in PICU.

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Appendix: GFRUP's study group on forgoing treatments

Data were collected in the NPICU/PICUs of the following centers: American Memorial Hospital, CHU de Reims, France; Hôpital Charles Nicolle, CHU de Rouen, France; Hôpital Arnaud de Villeneuve, CHU de Montpellier, France ; Hôpital Clocheville, CHU de Tours, France; Hôpital des enfants, CHU de Toulouse, France; Hôpital Hautepierre, CHU de Strasbourg, France; Hôpital Jeanne de Flandre, CHU de Lille, France; Hôpital Femme Mère-enfant, Hospices Civils de Lyon, France, France; Hôpital Morvan, CHU de Brest, France; Hôpital Necker, Assistance Publique-Hôpitaux de Paris, France; Hôpital Nord, CHU de Grenoble, France; Hôpital Reine Fabiola, Bruxelles, Belgium; Hôpital Robert Debré, Assistance Publique-Hôpitaux de Paris, France; Hôpital Saint Pierre, CHU de Besançon, France; Hôpital Trousseau, Assistance Publique-Hôpitaux de Paris, France.

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Competing interests The authors declare that they have no competing interests.

Table 1: Comparison of children for whom appropriateness of life sustaining treatment was questioned with children for whom it was not.

	Children for whom LST was not questioned Median (Q1-Q3)	Children for whom LST was questioned Median (Q1-Q3)	Comparison
All children	***n = 5294***	***n = 308***	
Age (months)	13 (2 – 69)	4 (0 - 25)	p<.00001
Length of stay (days)	2 (1 – 5)	9 (4 – 17)	p<.00001
Mortality predicted by PIM2 score (%)	1.5 (.8 - 4.8)	10.1 (3.5 – 36.0)	p<.00001
PELOD score at admission	10 (1 – 11)	12 (10 – 22)	p<.00001
POPC at admission *	1 (1 – 3)	4 (2 - 4)	p<.00001
POPC at discharge	1 (1 – 3)	6 (4 - 6)	p<.00001
Survivors	***n = 5073***	***n = 119***	
Age (months)	13 (2 – 69)	11 (2 - 53)	p=.50
Length of stay (days)	2 (1 -5)	11 (4 – 20)	p<.00001
Mortality predicted by PIM2 score (%)	1.4 (0.8 – 4.2)	5.8 (2.0 – 19.3)	p<.00001
PELOD score on admission	10 (0 – 11)	11 (10 – 21)	p<.00001
POPC on admission*	1 (1 – 3)	4 (3 – 4)	p<.00001
POPC on discharge*	1 (1 – 3)	4 (4 – 4)	p<.00001
Deceased children	***n = 221***	***n = 189***	
Age (months)	11 (1 – 57)	2 (0 – 13)	p<.00001
Length of stay (days)	1 (0 – 5)	8 (3 – 16)	p<.00001
Mortality predicted by PIM2 score (%)	21.7 (6.0 – 65.6)	14.7 (4.3 – 49.0)	p=.06
PELOD score on admission	22 (12 – 41)	13 (11 – 30.5)	p<.00001
POPC on admission*	1 (1 – 4)	3 (1 – 4)	p=.0003

(*): Excluding newborns – PIM2 score: Pediatric Risk of Mortality score [21] – PELOD score: Pediatric Logistic Organ Dysfunction score [22], POPC; Pediatric Overall Performance Category [23].- LST: life sustaining treatment.

Table 2: Motivations of the 269 anticipated decisions regarding LST, according to the classification of the Royal College of Paediatrics and Child Health [17]

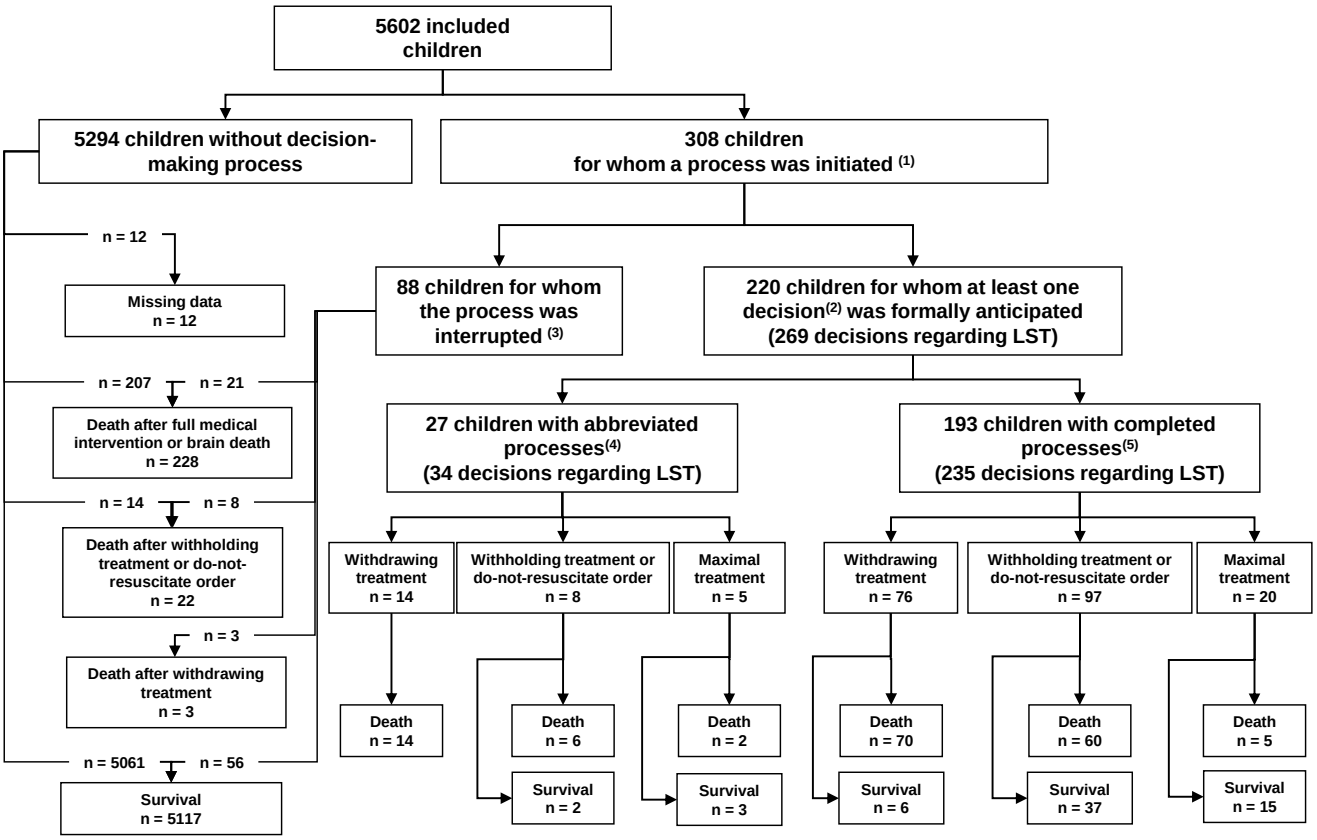
	All decisions n (%)	Withholding decisions and DNRO n (%)	Withdrawing decisions n (%)	Maximal treatment decisions n (%)
Missing data for decision making	6 (2.2)	NA	NA	6 (13.6)
No consensus	8 (3)	NA	NA	8 (18.2)
Predictable permanent vegetative state	59 (21.9)	29 (21.8)	30 (32.6)	NA
No chance situation	44 (16.4)	19 (14.3)	25 (27.2)	NA
No purpose situation	77 (28.6)	48 (36.1)	29 (31.5)	NA
Unbearable situation	9 (3.3)	4 (3)	5 (5.4)	NA
Unclassifiable or not applicable	66 (24.5)	33 (24.8)	3 (3.3)	30 (68.2)
Total	269 (100)	133 (100)	92 (100)	44 (100)

DNRO: do-not-resuscitate order – NA: not applicable

Table 3: sedative treatment in the 104 children for whom it was modified after the last decision

	New sedative treatment				Maintained sedative treatment			
	Normal dose	Double to triple dose	Quadruple to quintuple dose	More than quintuple dose	No change in dose	Double to triple dose	Quadruple to quintuple dose	More than quintuple dose
Benzodiazepines	15	14	4	1	16	20	7	4
Opiates	23	12	4	2	15	22	5	8
Barbiturates	8	6	1	5	0	1	0	9

Figure 1: Study flow chart



1 Defined as the record of a date of initiation of a decision-making process.
2 Defined as the record, prior to the terminal event, of at least one choice by PICU staff among four possible options: full medical intervention, DNR, withholding LST, withdrawing LST, associated with the record of the corresponding date.
3 Defined as the record of a date of initiation of a decision-making process but the absence of data concerning decision-making process.
4 Defined as the record of at least a decision with the corresponding date but the absence of data concerning decision-making meeting or bedside discussion
5 Defined as the record of an anticipated decision regarding LST and the record of a decision-making meeting.

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